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THE CHALLENGES OF DISABILITY IN PAKISTAN: LISTENING TO THE VOICES OF MOTHERS

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Abstract

This study was conducted with the aim to explore the experiences of mothers in dealing with children having disabilities in Rawalpindi, Pakistan. Through random sampling method 154 mothers of physically handicapped children studying in pre-schools and primary schools were selected as respondents. The main instrument used for data collection was researcher administered questionnaire. The data highlights that the disability of the children had been unexpected for all the mothers who participated in this research. The mothers reported to have been shocked (56%) and apprehended about the future of the children (41%). Some of the emotional problems encountered by the mothers included feelings of confusion and depression. The majority of the respondents had taken measures to treat the disability with the help of experienced professionals (51%) and by using therapeutic therapy (05%). The data demonstrates that measures taken by mothers to facilitate their children included seeking help from internet and engaging with support groups and friends.

Keywords: Disability, Stress, Mothers, Strategy, Support group

Introduction

Disability is a complex, dynamic, multidimensional and contested issue. The term is used to refer to individual functioning including physical impairment, sensory impairment, cognitive impairment, intellectual impairment, mental illness and various types of chronic disease (Brett, 2002). Academic research has explored the social problems faced by special people as well as the challenges encountered by their families and friends. The birth of a child with a disability in a family has a profound effect on the entire family. It brings immense changes in the family which is often likely

to persist for a long time. It brings about challenges that parents are often unprepared for (Martin & Colbert, 1997; Simmerman, 2001).

Children with disability require special attention from parents often at the cost of time and money. Research highlights that parents of children with disabilities often quit their jobs, reduce the number of working hours, or change jobs to be able to take care of the special children in a better way (Brennan & Brannan, 2005; Porterfield, 2002; Rosenzweig et al., 2002; Rosenzweig & Huffstutter, 2004; Thyen et al., 1999). This is likely to happen in the absence of family support and sufficient resources (Barnett & Gareis, 2008). Depending on whether the disability is mental or physical and depending on its severity, the families of disabled children may have more financial difficulties, more strained emotional relationships among family members, modified work and leisure activities, a limited social life, and greater time constraints due to care demands (Olsson & Hwang, 2003).

Research evidences that parents of children with disabilities tend to experience higher levels of stress compared to those parents having normal children (Sanders & Morgan 1997). Studies have also highlighted feelings of frustration or alienation (Fish, 2006). Research exploring the experiences of parents in raising children with disability has reported feelings of loss, grief and burden (Lalvani, 2011). Recent studies show that feelings of parents are not always negative (Ferguson, 2007) and it has been suggested that the interpretation of children with disability is dependent on socio cultural meaning ascribed to disability (Fisher & Doodley, 2007).

In the context of South Asia, having a child with a disability is often perceived negatively and such children are stigmatized. Often superstitious beliefs are associated with such individuals and these are considered as an outcome of divine punishment because of sins committed by the parents during their life time. Parents have been reported to have feelings of shame, embarrassment and guilt. Consequently while attempting to keep the matter private parents fail to seek assistance to treat the children. However, recent research in the context of South Asia shows that there has been positive change in public perceptions about disability. This has been reported to have been especially true among South Asian Muslim parents having children with autism. These parents perceived their disabled children as a gift from Allah and believed that they had been chosen by God to take care of them (Jegatheesan, 2009).

In Pakistan being a disabled person comes with full of challenges. Despite efforts of national and international organizations for the inclusion of special children in all walks of life constrains remain. There is absence of totally developed education system for special children. Majority of the existing special schools are in the developed cities of the country (UNICEF,

2013). Students with disability also encounter challenges at university level and at work (Ali & Hameed, 2015; Miles & Miles, 1993).

This paper aims to investigate the experiences of mothers in dealing with children having disability. We perceive disability as a socially constructed phenomenon and its meaning embedded in the socio cultural context. By highlighting the voices of mothers in this paper we hope to unveil the issues they encounter in dealing with their special children on daily basis. We would also like to acknowledge the efforts they are undertaking personally to facilitate the lives of their special children. The data will be useful to provide policy measures for the provision of support group for parents especially the mothers.

Literature Review

Academic research has highlighted that when parents first come to know about the disability of their child, their initial aim is to help the child. How the disability will affect the family and how they will bear the costs are considered secondary. Nevertheless, having a disabled child in the family comes with challenges since treatment including medication counseling and later schooling involve a large amount of money. This is specially a problem for the low income families (Trute et al, 2007).

It has been reported that parents undergo several stages when dealing with children with disability in the family. The first phase is termed as the shock stage which is typically the instantaneous response of a parent after the diagnosis of their child. In this stage, the parent may be numb and unable to incorporate or realize the scale of the event. Moreover, the parent may be disorganized emotionally confused, paralyzed, doubtful, and irrational. The second phase is referred to as the reaction phase which is characterized by grief, sadness, and anxiety. Parents may sometimes feel helpless, lost, and extremely insecure of themselves. Such feelings can be overcome through personal resources and the ability to cope flexibly with problems. A favorable environment can also prove relevant in providing some feeling of safety and protection under such circumstances (Kao & Schneider, 1996).

Since children with disabilities require special attention, and often trained care providers having a child with disability brings extra challenges in families where both parents work (Brennan et al., 2003). Often employed parents are concerned in finding childcare that is reliable, affordable, and flexible. Parents have reported that it is challenging to find child care suitable to care for their special children (Emlen, 2010).

To address these concerns related to child care families often make their own arrangements. Parents take turns in looking after the child at home and often siblings too take over some of the responsibilities (Rosenzweig et al., 2011). Parents have also been reported to seek assistance from friends

and family. However, research has demonstrated these arrangements often lead to poor psychological and physical health states for parents and other family members (Finston, 1990).

The child's disability affects the entire family yet research evidences that the disability impacts mothers more than it does fathers (Gray, 2003; Hastings et al., 2005; Oelofsen & Richardson 2006). It has been found that in most cases, it is the mother who gives up her job or career to stay home and she is the one to take over most of the childcare responsibilities too (Hedov et al., 2000). Even if they continue working, the mothers of disabled children have been reported to have more sick days and more absences from work to care for sick children as compared to mothers of normal children (Powers, 2001; Westbom, 1992).

Research highlights that mothers and fathers are likely to be effected in different way because of the disability of a child. It has been reported that fathers are not affected personally but because of the stress experiences by their wives (Gray, 2003). According to Gray (2003) this can be explained by the gender roles assigned to men and women at home and at work. Difference was also reported in the coping strategies among men and women. Women tend to be open about their feelings while men suppress them and work till late at work (Gray, 2003).

The different factors related with caring for children with disability include support system at home, cultural values and beliefs, and financial resources. It is also important to have support mechanism from the state in order to facilitate parents in dealing with their disabled children. Some of the actors who are involved in provide this support in many countries include social welfare groups, Churches and charities. Physicians and counselors can also play a role by suggesting help (Brennan & Brannan, 2005).

While raising their special children parents experience several problems including sadness, fear and worry. In addition parents have also to encounter the reaction from relatives and society about their disabled children. Some of the problems working women encounter in particular include lack of child care, lack of understanding at workplace, and societal pressure demanding that women with special children should not be working (Kagan et al, 1999; Shearn & Todd, 2000). In response to such constraints many women attempt to make personal adjustments. While some change their routine others have been reported to return to traditional home (Oelofsen & Richardson, 2006).

In addition, families of children with disabilities have also been reported to stop socializing and tend to isolate themselves from their support circles including family and friends. Some families migrate to new places others give up on existing friends and interact with new people having similar conditions. This makes life easier for them since people in the special

needs community tend to understand the problems they are facing and the feelings they are going through (Brennan et al., 2003; Hastings et al., 2005).

Methodology

The data for this study comes from a survey carried out with the help of a researcher administered questionnaire. The universe of the study was Wah Cantt in Rawalpindi city in Pakistan. It included 253 special children from three schools including Nashemen School, Learning School and Edo School. Data was collected from mothers of handicapped children who were in pre- school and primary schools. A sample of 154 students having disability was selected by using probability sampling including simple random sampling. Among these students 20 were selected from Learning School, 20 from Edo School and 114 from Nashemen School. Among the selected respondents 60 children were blind and 94 children were duff and dumb. The details of the parents of the selected students were obtained from the schools and the mothers were contacted to obtain their willingness to participate in the research. Informed consent of the informants was taken prior to the interviews. The sample size was selected by using the following formula.

$$n = \frac{N}{1+N(e)^2}$$

Pretesting of 15 was carried out prior to the final survey to check the reliability of the questionnaire. The data was coded (Bobbie, 2015) and has been analyzed by using SPSS.

Findings and Discussion

Table 1 describes the general characteristics of the respondents. According to the table the majority i.e. 62% respondents belonged to the age group of 31 – 40, 24% belonged to the age group of 20 – 30 and 14% belonged to the age group 41 – 50. The education level of the respondents also varied. The majority i.e. 67% was graduates and 21% were post graduates.

Table 1: General characteristics of the respondents

Categories	Percentage	Categories	Percentage
Age		Education	
20-30	24	Higher Secondary	12
31-40	62	Graduate	67
41-50	14	Postgraduate	21
Family size		Occupation	
0-5	56	Teacher	30
5-10	32	Government servant	53
10-15	7	Doctor	3
15-20	5	Bankers	14

Source: survey

As the table illustrates all the respondents were employed and among these 53% were government employees working in different capacities 30% were teachers in private schools, 14% were in banks and 3% were doctors. The table also shows the family size of the respondents. The majority 56% lived in nuclear families.

Table 2: Age of the Special Children

No.	Category	Percent
1	3-5	18
2	5-7	47
3	7-9	18
4	9-11	17

Source: survey

Table 2 illustrates that the majority i.e. 47% disabled children were in the age group of 5 – 7. 18% were in the age group of 3 – 5, 18% were in the age group of 7 – 9 and 17% were in the age group of 9 – 11. All the disabled children of the respondents attended schools for physically handicapped children located in the study area. Since physically handicapped children always require supervision, the mothers were asked about the care takers of the children.

Table 3: Care Taker after School

No.	Category	Percent
1	Family/relatives	71
2	Servant	29

Source: survey

Table 3 shows that the majority 71% parents reported that the immediate family or relatives living nearby took care of their children after school. 29% reported to have servants to take care of their children after school.

Table 4: Initial reaction to the Disability

No.	Category	Percent
1	Concerned about the future	41
2	Worried about finance	3
3	Shocked	56

Source: survey

Table 4 indicates that when the respondents first came to know about the disability the initial concerns were related with the future of the children and the financial burden in treating the disability. The majority i.e.56% reported to have been shocked while 41% respondents were worried about the future of their disabled children. 3% reported to be worried about financial pressure. The respondents also reported to have difficulty in understanding the needs of the children and communicating with them.

Table 5: Emotional Problems

No.	Emotion problem faced by parents	Strongly agree %	Agree %	Disagree %
1	Depression	40	50	10
2	Fear	07	11	82
3	Confused	17	58	25
4	Guilt	01	03	96
5	Embarrassment	01	01	98

Source: Survey

Previous literature shows that knowing that a child is disabled comes as a shock for all parents. Stress, anxiety, depression and confusion are some major psychological pressures they have to deal with (Dixon et al., 2007). Table 5 shows that the mothers also encountered emotional problems when they heard about the disability of their children. The data illustrates that 50% respondents agreed and 40% respondents strongly agreed that they had been through depression when they came to know about the disability of their child. The majority i.e. 82% disagreed that they had the feeling of fear. However, 58% agreed that they had been confused initially. Feelings of guilt was reported only by 03% respondents who agreed while 96% disagreed that they had feelings of guilt while 98% disagreed that they had feelings of embarrassment when they came to know about the disability of their children.

Table 6: Measures Taken to Treat the Disability

No.	Category	Percent
1	Finding competent professional services	51
2	Understanding difficult behavior of children with disabilities	44
3	Using therapeutic therapy	05

Source: survey

Table 6 illustrates that the majority i.e. 51% respondents had made efforts in finding professional services to treat the disability. 44% responded that they attempted to understand the behavior of the disabled children in order to be able to treat their disabled children well at home. 05% reported to have used therapeutic treatment.

For including the disabled children in the mainstream society it is important that they should be considered equal to normal children and should be treated in such a way. One way to do this is to take these children to social events. For example, taking children to religious gatherings may help them make friends be vocal and active and independent. Taking children to such events may help them understand about different social gatherings where all age groups can enjoy. The respondents were asked if they preferred to take their disabled children to social events.

Table 7: Participation in Social Events

No.	Kinds of events	Yes %	No %
1	Religious gatherings	20	80
2	Wedding ceremonies	56	44
3	Official parties	46	54

Source: survey

Table 7 demonstrates that 20% respondents reported to take their children to religious gatherings while 80% didn't. 56% respondents reported to take their children to wedding ceremonies and 44% didn't. 46% respondents reported to take their children to birthday parties and 54% didn't. These figures show that the majority of the respondents did not prefer to take the disabled children to social events. This is the main reason that results in isolation of disabled children and may lead to problems in their personality development in later years. These children may feel excluded and neglected.

Though the respondents may not prefer to take the disabled children to social events involving official colleagues and neighbors but they did take them to public places without any hesitation.

Table 8: Engagement in Public Places

No.	Places	Yes %	No %
1	Mall	70	30
2	Park	85	15
3	Mosque	21	79
4	Friend's place	88	12
5	Relative's place	62	38

Source: survey

Table 8 shows that 70% respondents reported to take their children to Mall while 30% didn't. 85% reported to take their disabled children to parks and 15% didn't. Similarly the respondents also felt comfortable in taking the

children to friends and relatives places. 88% and 62% respondents reported to take the children to their close friends' and relatives places. 21% reported to take their along children to mosques for prayers while 79% didn't.

Table 9: Strategies used by Parents to Support their Special Children

No.	Supporting the Child	Strongly Agree %	Agree %	Disagree %
1	Through speech	48	41	11
2	Through action	32	35	33
3	Through internet	07	27	66
4	Through support groups	14	45	41
5	Through friends	31	61	08

Source: survey

The study demonstrates that parents make personal efforts to make the lives of their special children easier. Table shows that several strategies were reported by parents in this regards. For example, the respondents reported that they helped their children through speech (Table 9). This was strongly agreed by 48% and agreed by 41% respondents. Respondents also reported that they practically performed actions to facilitate their special children. This was strongly agreed by 32% respondents and agreed by 35% respondents. Some of the mothers also explained that they sought help from internet to support their children. This was strongly agreed by 07% and agreed by 27%. 66% did not agree to this since they did not have access or knowhow of internet. The mothers also gained assistance from support groups including social workers. This was strongly agreed by 14% and agreed by 45% respondents. 41% disagreed to it since they reported that they either did not have awareness or time to take the children to support groups. The respondents also reported to seek help from friends. This was strongly agreed by 31% and agreed by 61% respondents. 08% respondents disagreed to it.

Conclusion

The mothers who participated in this study reported to have experienced anxiety when they first came to know about the disability of their children. However, they were prompt to seek professional advice for treating the disability. Several measures were taken by the respondents to facilitate their special children. Some reported to seek help from internet and educated themselves about how they could engage with the special children and help them to live a normal life. Others gained assistance from support groups and friends to make the lives of the special children better. The findings illustrate that disability was not treated a taboo in the study context and the mothers reported to be comfortable in accompanying their special children while they visited public places, friends and relatives. However, the

majority were not very comfortable in taking their special children to official parties, religious gatherings and weddings. This indicates that disability may not be a taboo but mothers do have feelings of otherness for their special children. Considering the fact that parents reported stress in raising the special children it is suggested that counseling services should be available for parents to help them understand their children in a better way. Since the study was limited to the mothers alone it has not highlighted how the experiences of the mothers were different from the fathers. This is an area which can possibly be explored by future researchers.

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